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Prevalence of cancer chemotherapy-related problems, their relation to health-related quality of life, and associated supportive care: a cross-sectional survey

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Prevalence of cancer chemotherapy-related problems, their relation to health-related quality of life, and associated supportive care: a cross-sectional survey

Purpose: To identify the treatment-associated problems that most impact on patients undergoing cancer chemotherapy, how problems relate to experiences of supportive care and variations in experience between cancer treatment centres.

Methods: A survey administered to patients at six cancer centres in England explored variations of prevalence of 17 cancer chemotherapy-associated problems and associated supportive care. Problem items were identified as the most frequently experienced and severe when experienced in a scoping and consensus exercise. A health-related quality of life (HRQoL) measure, the EQ5D, was included to measure impact of problems.

Results: 363 completed questionnaires were returned (response rate 43%, median 61%). The most prevalent problem was 'tiredness/fatigued' (90%), followed by 'changes in taste & smell' (69%) and 'difficulty managing everyday tasks' (61%). Significant variations in problem prevalence existed between centres and some common problems were rarely reported in the literature. Regression analysis found almost all problems were significantly associated with HRQoL, with social/emotional problems having as much impact on HRQoL as physical/psychological side-effects of treatment. Greatest effect size was for 'difficulty managing everyday tasks'. Respondents reported significant variations in supportive care between centres, with more supportive care received for physical/psychological problems than for social/emotional problems. Findings indicated patients who received increased supportive care experienced less severe problems.

Conclusion: The most common and distressing chemotherapy-associated problems were identified. These problems are mitigated by quality supportive care. Routine measurement and monitoring of problem items and supportive care are warranted to facilitate benchmarking and service improvements both within and between cancer centres.

INTRODUCTION

More than 165,000 patients currently receive chemotherapy each year[1], which is increasingly administered in ambulatory outpatient rather than inpatient care settings[2,3,4,5,6]. Despite increasingly aggressive regimens, few patients in the UK will require hospitalisation[7]. Nevertheless, patients undergoing chemotherapy experience substantial levels of distress across a wide range of physical and psycho-social problems[8,9,10]. The shift to outpatient chemotherapy provision means patients and their families are likely to encounter problems outside the hospital setting, without immediate access to professional health advice. Moreover, patients will sometimes abandon chemotherapy prematurely as a result of treatment-associated problems, despite potentially life-threatening consequences[10].

Managing the supportive care needs of cancer patients involves helping them and their family cope with problems associated with cancer and treatment[11], and is fundamental to delivering high quality, person-centred care[12,13,14]. To ensure quality supportive care for patients undergoing chemotherapy, we need to understand the problems they experience and which have greatest impact. A scoping review by this research team identified studies that reported the prevalence of a range of chemotherapy-associated problems[8]. These studies have usually been limited to physical and psychological symptoms such as fatigue, nausea or depression. While the impact of chemotherapy on social and emotional issues have previously been explored, including personal relationships, work and finances[15,16,17], very few studies have reported the prevalence of such problems. Nevertheless, where prevalence was reported, social and emotional problems were found to be as prevalent as physical side-effects[18,19]. Recognition of the full range of the most common chemotherapy-associated problems would allow a more patient-centred and holistic approach to supportive care.

In our previous research, variations in rate of both problems and support experienced by patients were identified across ambulatory chemotherapy units[9,20]. For example, prevalence of moderate

to severe nausea ranged between 24%-73% at different sites, while those reportedly not receiving practical advice for managing their symptoms ranged from 1%-13%[9]. Such wide variations in satisfaction and experience with cancer care reflects previous international evidence[21,22,23,24,25].

In order to benchmark and improve health service quality and outcomes between units and over time, suitable measurement tools are required. Patient-reported outcome measures (PROMs) and experience measures (PREMs) are increasingly recognised internationally as an important tool for such situations[26]. Concern to address variations in care quality in the UK has led to the first national PREM initiative to benchmark and monitor patient experience of care. The national Cancer Patient Experience Survey (CPES) now regularly explores care experienced by cancer patients in England and has identified improvements over time[27]. However, limitations would exist for any national PROM/PREM survey designed for use across different treatment types and care sectors, and only four CPES survey questions specifically ask about care as a day patient or outpatient. Furthermore the results do not give any specific indication of the problems that patients experience and whether services are responding effectively to provide support. Such data is therefore of limited use when seeking to address the specific experience of patients in an ambulatory chemotherapy environment and to improve patient reported outcomes and quality of supportive care received. This study therefore aimed to identify the most common problems experienced by people with cancer receiving ambulatory chemotherapy and which had greatest impact, and to explore how these problems relate to peoples' experiences of supportive care.

MATERIAL AND METHODS

Development of questionnaire

Invited clinicians (n=32) at six participating cancer centres, together with cancer survivors of a range of tumour sites (n=41) recruited via 'Cancer Voices Online', formed a reference panel to aid selection

of items for the questionnaire via an online survey. Panel members were presented with a list of 27 common problems identified from a systematic review[8], supplemented by common problems identified in our previous study[9,20]. All panel members were asked to assess from their experience as patients or clinicians the *frequency* of each problem and how often these problems were severe. Panel members were asked to identify up to three additional problems they thought were at least as common as those on the list and rate them in terms of frequency/severity. Items were ranked in two lists, frequency and severity, with items that appeared in the top ten of either list selected for inclusion in the final questionnaire. The top ten only were selected from each list to ensure a manageable number of items. There was some overlap between these two lists, with items appearing on both giving a final total of 17 items for the questionnaire. Panel members were then requested to assess their experience of supportive care to manage both physical and psychological problems (i.e. 'losing your hair' or 'low in mood' and social and emotional problems 'i.e. difficulties in relationships with family and friends' and 'financial worries'). (always/usually/ occasionally/never). We also included three questions for review regarding preparation for what problems to expect and who to contact in emergencies. The draft questionnaire comprised the final list of problems, asking respondents about severity (not at all/mild/moderate/severe), questions about levels of supportive care and socio-demographic characteristics. Respondents were asked to report any problems they were experiencing in addition to the 17 listed in the questionnaire, and their severity (mild/moderate/severe). An existing validated health-related quality of life (HRQoL) measure, the EQ5D[28], was also included. HRQoL is a multi-dimensional concept that includes physical, mental, emotional and social functioning, and focuses on the impact health status has on quality of life. The EQ5D measure comprises five domains from which a single summary score can be calculated: mobility; self-care; usual activities; pain/discomfort; anxiety/depression. The EQ5D was used to validate the included problem items by measuring their association with HRQoL. The 2-page, 4-side instrument underwent cognitive testing with a small number (n=12) of patients attending chemotherapy outreach services at two locations. Slight amendments were subsequently made to

the wording of the questionnaire. The instrument took patients approximately 15 minutes to complete.

Setting and participants

The finalised paper-based questionnaire was distributed to chemotherapy patients at six cancer centres across England. Our aims were to assess prevalence of problems and variations in prevalence and supportive care between centres, to assess acceptability and feasibility of use (e.g. by monitoring rates of response and missing data) and to conduct preliminary validation by measuring associations with the EQ5D.

National Health Service (NHS) cancer treatment and supportive care services in the UK are free at the point of use, should be of consistent quality across the country and be designed around the needs of patients[13,29]. Supportive care services available include specialist nurses (Clinical Nurse Specialist, Nurse Consultants and Nurse Practitioners) although provision varies by centre and tumour site, with variation in these services associated with known variation in patient experience[30]. All six collaborating centres were NHS ambulatory cancer units that provided similar chemotherapy treatment pathways to patients with a range of primary cancer sites, though they varied in size from regional cancer centres to local hospital sites.

Each centre agreed to invite 120 individuals who attended outpatients and fulfilled the following inclusion criteria, to complete a questionnaire:

- Patients receiving 'curative' chemotherapy treatment only;
- Patients receiving chemotherapy for any primary cancer diagnosis;
- Patients receiving any cycle of chemotherapy treatment, except their first cycle.

Staff sickness at centre 4 during the data collection period, including the nurse co-ordinating the study, meant only 64 outpatients were invited to complete the questionnaire at that site. Any questionnaires not administered were returned to the research team.

Data collection occurred between 20/11/2013 and 03/01/2014. Patients were encouraged to return the completed questionnaires to a collection box in each unit. However, some patients preferred to complete questionnaires at home and pre-paid envelopes were provided for these to be returned.

ETHICS

This work was conducted as a service evaluation, assessed as not requiring approval by the National Research Ethics Service. Local approvals were gained from R&D departments at participating cancer treatment centres. All participants were given full information about the project and consent was indicated by completion and return of questionnaires. All questionnaires were anonymous.

ANALYSIS

Data were entered into Stata v13.1. Descriptive statistics and χ^2 tests were used to explore demographic data, reported frequency and severity of problems and experience of supportive care. Each participant's single index EQ5D scores was calculated (summarising five domains: mobility; self-care; usual activities; pain/discomfort; anxiety/depression). Univariate and multivariate linear regression analysis explored associations and patterns between reported severity of problem items, summary EQ5D scores and supportive care received. All regression analyses were controlled for age, gender and treating cancer centre.

RESULTS

Overall survey response rate was 43% (n=363), with a range of 20%–78% between sites (median 61%) (Table 3). Respondents included more women than men, and breast was the most frequent tumour site (24.8%), followed by bowel, lung and gynaecological. The highest proportions of respondents were undergoing their seventh or third chemotherapy cycles. Questionnaires were completed in their entirety by 70.5% (n=256/363) of participants; a further 87 had either one or two missing items, indicating question items were acceptable to participants. Analysis of variations in response between centres found significant differences in gender ($\chi^2_{(5)}=17.2$, $p=.004$) and tumour type

($\chi^2_{(60)}=138.2$, $p<.001$), but no significant differences between age groups of respondents or the cycle of chemotherapy they were receiving.

Problem prevalence and severity

The problem most frequently reported was 'tiredness, fatigued or lacked energy', with 90% of respondents reporting it represented a mild, moderate or severe problem for them (Table 1). Ten of the seventeen problems were experienced by more than 50% of respondents. Although 'losing your hair' was experienced by less than half of respondents (46%), it was nevertheless the condition that the highest proportion of those who did experience it reported it to be 'severe' (13%). Least frequently reported were 'difficulties in relationships with family or friends', although it was still a problem for almost a fifth (19%) of participants. Significant differences in reported prevalence were found to exist between centres for seven problems: 'tired, fatigued or lacked energy' ($\chi^2_{(15)}=29.300$, $p=.015$); 'trouble sleeping' ($\chi^2_{(15)}=30.600$, $p=.010$); 'feeling sick (queasy/nausea)' ($\chi^2_{(15)}=26.681$, $p=.031$); 'losing your hair' ($\chi^2_{(15)}=32.213$, $p=.006$); 'low mood' ($\chi^2_{(15)}=36.138$, $p=.006$), 'financial worries' ($\chi^2_{(15)}=26.680$, $p=.031$) and 'diarrhoea' ($\chi^2_{(15)}=25.667$, $p=.042$). In total, 80 respondents provided 105 additional problems, almost all of which could be categorised within our working typology, with the most often reported additional problems being 'tingling/numbness' ($n=16$), 'pain' ($n=14$) and 'skin problems' ($n=11$). Nevertheless, all additional problems were substantially less frequently reported than items already listed in the questionnaire.

Association of problem items with HRQoL

Individual summative EQ5D scores incorporated the full range of those possible with 24 individuals indicating their health was the best they could imagine (100) and one indicating it was the worst (0). The median EQ5D summative score was 75 (mean 72), with the interquartile range (IQR) between 60 and 85. This indicates that overall respondents felt their health to be good, although several outliers

indicated they were experiencing very poor health. There were also significant differences in reported EQ5D scores between centres ($p=.038$).

Univariate regression was used to explore associations of EQ5D against each of the problem items (ranked: none/ mild/ moderate/ severe). Regression co-efficients indicate a negative correlation exists between severity of problems and reported HRQoL, with the effect being monotonic for most problems, i.e., the worse a problem was experienced, the lower the reported HRQoL (table 4). All problems were significantly associated with lower HRQoL, at least at some level of severity (mild/ moderate/ severe) when compared to absence of the problem, with the exception of 'losing your hair'. The strongest effect sizes existed for 'difficulty managing everyday tasks or work' when experienced as severe ($B=-.472$), followed by 'low in mood' ($B=-.288$) and 'unable to concentrate, forgetful or confused' ($B=.265$), or when 'difficulties in relationships with family or friends' was experienced as moderate ($B=-.229$). Notably, while being 'tired, fatigued or lacked energy' was the most prevalent problem reported by 90% of respondents, its impact on HRQoL when experienced as mild ($B=-0.074$) or moderate ($B=-0.0143$) was lower than that for relationship difficulties (mild; -0.113 ; moderate: -0.229). The impact of nausea and vomiting were lower still.

Results from multivariate linear regression suggested that when all problem items were included within a model, few had a consistent predictive relationship with HRQoL. The largest and most consistent effect size was for experiencing 'difficulty managing everyday tasks', and impact on HRQoL was found significant at any degree of reported severity (mild: $B=-0.058$, $p=.027$; moderate: $B=-0.120$, $p=.001$; severe: $B=0.355$, $p<.001$). The second largest effect size was for 'difficulties with relationships with friends and family', ($B=-0.137$, $p=.199$) and thirdly, 'pain/irritation at injection site' ($B=-0.116$, $p=.121$), when both are experienced as severe. This may in part be explained by the broadness of the item 'difficulty managing everyday tasks', which may incorporate impact from several of the other more narrowly defined items, i.e. 'feeling anxious', 'low in mood' and 'financial issues'.

Variation in supportive care for problems

Table 2 shows whether respondents received supportive care (always/usually/occasionally/never) for physical/psychological problems and social/emotional problems. There were clear differences in the supportive care provided for these two types of chemotherapy-associated problem, and large and statistically significant variations were found to exist between centres in almost all the reported aspects of support. Regarding physical and psychological problems, 70.7% (n=252) of respondents reported staff 'always' ask them about their problems, with a range between centres of 47.2% and 90.2%. Responses to the other questions in this section found that: 63.9% (n=225) of respondents reported staff were 'always' aware of their problems (range between centres: 43.3%-83.3%); 69.0% (n=352) reported staff 'always' provided useful information (range: 51.0%-83.6%); 68.8% (n=241) reported staff 'always' provided practical support (range: 50.2%-84.2%), and; 57.8% (n=207) reported they 'always' felt confident in their ability to manage the physical and psychological symptoms they were experiencing (range: 50.6%-57.8%).

The responses to questions asked about social and emotional problems indicated far lower levels of supportive care, and again significant variations were found between centres. Only 23.5% (n=82) respondents reported staff ask them about social and emotional problems (range between sites: 13.0%-36.6%); 30.6% (n=101) reported staff were 'always' aware of their problems (range of 13.6% - 40.2%); 32.8% (n=109) reported staff 'always' provided useful information (range: 22.7%-44.2%); 34.0% (n=113) reported staff 'always' provided practical support (range: 27.2%-43.4%, $p < .001$), and; 47.2% (n=162) reported they were 'always' confident in their ability to manage social and emotional problems they were experiencing.

Respondents were asked three general questions regarding the preparation they had received for managing their own problems. For each of these questions the majority of respondents reported they were prepared and there were no significant differences found between centres: 88.9% (n=313) of respondents reported they were 'always' confident in knowing who to contact or what to do if

they experienced any of the listed problems ($\chi^2_{(15)}=18.322$, $p=.246$, range between centres: 81.4%-95.8%); 86% (n=306) reported they were 'always' confident they knew what problems would require them to take emergency action ($\chi^2_{(15)}=9.788$, $p=.833$, range 80.3%-90.4%), and; 85% (n=304) reported they had been given the information they needed to prepare them before they started their treatment ($\chi^2_{(15)}=20.543$, $p=.152$, range: 76.7%-94.5%).

Univariate regression was used to explore associations between specific problem items (whether experienced moderately or severely) and aspects of supportive care (whether experienced usually or always) (Table 5). In many instances, fewer respondents experienced particular problems either moderately/ severely when they received appropriate supportive care 'usually or always' than those who received supportive care only 'occasionally or never'. For example, 46% (n=145) of respondents who reported they always or usually received 'useful practical support' from staff to help manage problems experienced severe or moderate 'tiredness, fatigued or lacked energy', compared with 69% (n=20) of those who only occasionally or never received such support. Associations between supportive care and problems were significant for six problem items, including all three categorised as social and emotional ('tired, fatigued or lacked energy'; 'trouble sleeping'; 'pain or irritation at injection site'; 'diarrhoea'; 'difficulty managing everyday tasks'; and 'difficulties in relationships with family or friends'), with increased supportive care related to decreased problem severity. This finding indicates that for these problems at least, quality supportive care may make an important difference to the HRQoL of patients.

DISCUSSION

This study identified 17 of the most prevalent and severe chemotherapy-associated problems facing individuals undergoing chemotherapy for cancer. A survey incorporating these problem items found the most frequently reported were tiredness/fatigue, problems with taste and smell and problems completing everyday tasks or work. Overall, response rate was comparable with the primary care postal survey[31], but varied widely between centres partly due to sickness of individual staff

members responsible for questionnaire administration. While significant variations also existed between centres in terms of gender and tumour site, these variables were controlled for in analysis.

All included problem items were found to be independently predictive of decreased HRQoL, and almost all of them had significant association with HRQoL. When combined in a multivariate model the item 'difficulty with everyday tasks and work' had the largest and most consistent effect size and was the only item that had a significant association with HRQoL. While this finding might suggest this one item to be the most useful of the problems for identifying the impact of chemotherapy on patients, it would not be a sufficient measure by itself given that it was neither the most prevalent problem item, nor the most severe when experienced.

Emotional and social problems were found to be as prevalent amongst survey participants as some physical and psychological symptoms. Moreover, difficulties with relationships (the least prevalent problem amongst this participant group) were found to have a much stronger effect on HRQoL when experienced as mild or moderate than tiredness/fatigue (most prevalent problem). An emerging shift from concerns about physical side-effects to psychosocial issues was identified almost two decades ago[32], and more recently Carelle et al.[3] found the most troubling problem faced by patients to be psychological. Our scoping review also found issues such as difficulties with relationships and worries concerning finances were bothersome for some individuals despite their relevance rarely being reported in the literature[8]. This may be because while effective interventions and drugs are widely available to address treatment toxicities, support interventions for emotional and social issues have not been as well developed. The fact that research to date has given little attention to the prevalence of these concerns is likely due to multiple reasons, but may partly stem from a perception that these are not significant problems for patients. This study indicates that contrary to this perception, psycho-social issues experienced by people receiving chemotherapy can significantly impact upon their HRQoL.

The survey included questions requesting patients to report the quality of supportive care they had received from staff for their chemotherapy-associated problems. Findings indicate that those patients always or usually receiving supportive care for problems experienced them as less severe, sometimes significantly less, than those who never or rarely received supportive care. The study also found that while very few respondents reported that they never received supportive care for physical and psychological problems, over a fifth reported they never received such support for social and emotional problems. This finding indicates health professionals prioritise physical and psychological problems, and attribute less importance to social and emotional problems. Effective communication between clinicians, patients and their families is an essential part of supportive care, and reduces anxiety and depression and promotes emotional functioning, HRQoL and improved outcomes[34,35]. Nevertheless, as previous evidence has also shown, problems faced by cancer patients are frequently undetected by health care professionals[18,36, 37], and patients often remain unable to manage their symptoms through a lack of information and communication with health professionals[38].

Significant variations in symptom prevalence and supportive care received were reported between collaborating cancer centres, which may be partly due to differences in patient expectations, socio-demographic characteristics, and tumour and treatment types. Variations may also be associated with different levels of training and the skill-mix of staff within different units, organisational characteristics including leadership and the coordination of care[30,39,40]. Chemotherapy-associated problems are experienced subjectively by patients[41,42], and different problems will be associated with different chemotherapy regimens[43,44]. Moreover, reports of the problems cancer patients perceive most bothersome change from one decade to the next[33], which may be due to advances in chemotherapy and associated supportive treatments. If providers were aware of the prevalence with which the most common treatment-related problems were experienced by patients receiving chemotherapy in their unit, then service changes might be facilitated to address the related supportive care needs.

Given the prevalence and impact of these problem items on HRQoL, the mitigating effect of supportive care, and the variations found to exist between centres, a mechanism for assessing quality of care in ambulatory cancer units might facilitate service improvements. Given our findings, any PROM/ PREM developed for this purpose would need to include all 17 problems identified by this study if the full potential impact of chemotherapy on patients was to be adequately reflected. The future research implications in this area are to determine the extent to which service providers are aware of these problems and their impact, and whether routine use of a PROM/PREM based on these items to monitor care quality could effectively target improvements to supportive care.

Limitations of the study

Administration of questionnaires was delegated to collaborators within each centre, but while response rate was low at one centre (20%) it was 57% or higher in all other centres. Our convenience sample may not be entirely representative of the population of chemotherapy patients (nor centres), and some bias may exist as respondents were self-selecting. Nevertheless, the high prevalence of problems amongst participants is unlikely to be purely a selection effect, and problem prevalence might indeed be higher than reported. Despite positive associations between respondents reportedly receiving greater supportive care and experiencing problems less severely, no causal direction of these associations can be claimed. Finally, disease progression may negatively impact upon symptom prevalence, but as data on patient performance status were not collected in this study, we cannot account for its possible impact on our results.

CONCLUSION

For patients receiving cancer chemotherapy, we have identified the most prevalent problems and those that have most impact on HRQoL. Some of these problems, particularly emotional and social problems, have rarely been reported in previous studies. We provide evidence that supportive care may mitigate problems and improve HRQoL, but that it is more often provided for physical and

psychological problems than emotional and social problems. Variations exist between centres both in problem prevalence and perceptions of supportive care received. While these differences may or may not be related to the quality of services provided, they clearly indicate the need for services to consider the specific supportive care needs of their patient populations when planning provision.

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Table 1: prevalence and severity of chemotherapy associated problems

Rank	Problem	Prevalence ¹	Severity				Association with centres
			Severe problem	Moderate problem	Mild problem	No problems	
1	Tired, fatigued or lacked energy	90%	11%	37%	42%	10%	$\chi^2_{(15)} = 29.300, p=.015^b$
2	Changes to your sense of taste or smell	69%	11%	24%	34%	31%	$\chi^2_{(15)} = 15.405, p=.423$
3	Difficulty managing everyday tasks or work	61%	4%	19%	38%	40%	$\chi^2_{(15)} = 10.976, p=.754$
4	Trouble sleeping	59%	9%	21%	29%	41%	$\chi^2_{(15)} = 30.600, p=.010^b$
5	Constipation	59%	9%	20%	30%	41%	$\chi^2_{(15)} = 22.102, p=.105$
6	Low in mood	56%	4%	16%	36%	43%	$\chi^2_{(15)} = 36.138, p=.006^b$
7	Feeling sick (nauseous/queasy)	56%	7%	15%	34%	44%	$\chi^2_{(15)} = 26.681, p=.031^b$
8	Feeling anxious	54%	5%	16%	33%	46%	$\chi^2_{(15)} = 14.631, p=.478$
9	Lost appetite/lost interest in food	54%	5%	17%	32%	46%	$\chi^2_{(15)} = 15.319, p=.429$
10	Unable to concentrate, forgetful or confused	52%	3%	11%	38%	48%	$\chi^2_{(15)} = 11.525, p=.715$
11	Losing your hair	47%	13%	14%	20%	54%	$\chi^2_{(15)} = 32.213, p=.006^b$
12	Sore mouth or tongue	46%	6%	12%	28%	54%	$\chi^2_{(15)} = 21.364, p=.126$
13	Diarrhoea	39%	4%	12%	23%	61%	$\chi^2_{(15)} = 25.667, p=.042^b$
14	Sickness (vomiting)	35%	4%	10%	21%	65%	$\chi^2_{(15)} = 20.660, p=.148$
15	Financial worries	31%	4%	11%	16%	68%	$\chi^2_{(15)} = 26.680, p=.031^b$
16	Pain or irritation at your injection / infusion (needle) site	30%	2%	8%	20%	70%	$\chi^2_{(15)} = 14.728, p=.471$
17	Difficulties in relationships with family or friends	19%	1%	5%	13%	81%	$\chi^2_{(15)} = 5.285, p=.989$

Note: ^a Prevalence for each item is calculated by combining figures for participants who reported experiencing them as mild, moderate or severe;

^b p-Value statistically significant ($p<.050$)

Table 2: Survey responses to supportive care questions

Problem type	Frequency				Association with centre (Chi²)
	Always	Usually	Occasionally	Never	
Physical and psychological symptoms					
Do you get asked about your symptoms?	70.8% (252)	19.4% (69)	7.3% (26)	2.5% (9)	$\chi^2_{(15)}=64.744$, $p<.001^a$
Are all the staff who need to know aware of your symptoms?	63.9% (225)	29.5% (104)	4.5% (16)	1.9% (7)	$\chi^2_{(15)}=42.857$, $p=.002^a$
Do staff provide useful information to help you manage your symptoms?	69.0% (243)	23.3% (82)	6.8% (24)	0.9% (3)	$\chi^2_{(15)}=53.996$, $p<.001^a$
Do staff provide useful practical support to help your symptoms?	68.9% (241)	22.6% (79)	5.7% (20)	2.9% (10)	$\chi^2_{(15)}=42.086$, $p=.011^a$
Do you feel confident in your ability to manage the symptoms you are experiencing?	57.8% (207)	37.7% (135)	4.2% (15)	0.3% (1)	$\chi^2_{(15)}=17.705$, $p=.279$
Social and emotional problems					
Do you get asked about social, emotional or other problems?	23.6% (82)	25.0% (87)	26.7% (93)	24.7% (86)	$\chi^2_{(15)}=46.093$, $p<.001^a$
Are all the staff who need to know aware of social, emotional or other problems?	30.7% (101)	27.1% (89)	21.6% (71)	20.7% (68)	$\chi^2_{(15)}=36.456$, $p=.002^a$
Do staff provide useful information to help you manage social, emotional or other problems?	32.8% (109)	28.6% (95)	17.5% (58)	21.1% (70)	$\chi^2_{(15)}=40.514$, $p<.001^a$
Do staff provide useful practical support to help your social, emotional or other problems?	34.0% (113)	28.6% (95)	15.4% (51)	22.0% (73)	$\chi^2_{(15)}=30.298$, $p=.011^a$
Do you feel confident in your ability to manage the social, emotional or other problems you are experiencing?	47.2% (162)	36.4% (125)	10.8% (37)	5.5% (19)	$\chi^2_{(15)}=23.241$, $p=.079$
General support					
Are you confident that you know who to contact / what to do if you have such problems	88.9% (313)	9.1% (32)	1.4% (5)	0.6% (2)	$\chi^2_{(15)}=18.322$, $p=.246$
Are you confident that you know what problems would require you to take emergency action?	86.0% (306)	11.8% (42)	1.7% (6)	0.6% (2)	$\chi^2_{(15)}=9.788$, $p=.833$
Did you get the information you needed to prepare you before you started your course of treatment?	84.7% (304)	13.4% (48)	1.7% (6)	0.3% (1)	$\chi^2_{(15)}=20.543$, $p=.152$

Note: ^a p value statistically significant ($p<.050$).

Table 3: Site, demographic and treatment characteristics (n=363)

Characteristic		N=	%	Association with centres
Chemotherapy centre	Site 1	24	20	
	Site 2	68	57	
	Site 3	75	63	
	Site 4	50 ^a	78	
	Site 5	73	61	
	Site 6	73	61	
Gender	Male	127	35.0	$\chi^2_{(5)} = 17.2$ p=.004 ^b
	Female	197	54.3	
	Missing	39	10.7	
Age	18-30 years	2	0.6	$\chi^2_{(25)} = 23.2$, p=..562
	31-40 years	14	3.9	
	41-50 years	50	13.9	
	51-60 years	99	27.5	
	61-70 years	100	27.8	
	70 years plus	95	26.4	
Tumour site	Bladder/urological	11	3.1	$\chi^2_{(60)} = 138.2$ p<.001 ^b
	Leukaemia	11	3.1	
	Bowel	62	17.1	
	Breast	89	24.8	
	Gynaecological	35	9.7	
	Head & neck	5	1.4	
	Lung	42	11.7	
	Lymphoma	24	6.7	
	Oesophagus	18	5.0	
	Prostate	9	2.5	
	Stomach	10	2.8	
	Other	28	7.8	
Chemo cycle	Not started	3	0.9	$\chi^2_{(40)} = 43.4$ p=.327
	1	15	4.3	
	2	57	16.3	
	3	61	17.4	
	4	48	13.7	
	5	43	12.3	
	6	32	9.1	
	7	63	18.0	
	Finished treatment	28	8.0	

Note: ^a Site 4 only administered 64 questionnaires while all other sites administered 120;

^b p-Value statistically significant (p<.050)

Table 4: Problem-by-problem univariate analysis and multivariate full model (controlled for centre, age and gender)

Problem	Severity	Univariable Model				Multivariable Model			
		95% CI				95% CI			
		B	Lower	Upper	p-value	B	Lower	Upper	p-value
Difficulty managing everyday tasks or work	Mild	-0.131	-0.177	-0.085	<0.0005 ^a	-0.058	-0.109	-0.006	0.027 ^a
	Moderate	-0.216	-0.271	-0.161	<0.0005 ^a	-0.120	-0.188	-0.052	0.001 ^a
	Severe	-0.472	-0.589	-0.355	<0.0005 ^a	-0.355	-0.512	-0.199	0.000 ^a
Feeling anxious	Mild	-0.107	-0.157	-0.058	<0.0005 ^a	-0.018	-0.074	-0.037	0.521
	Moderate	-0.162	-0.224	-0.100	<0.0005 ^a	-0.056	-0.133	-0.021	0.154
	Severe	-0.190	-0.296	-0.083	0.001 ^a	0.069	-0.076	-0.213	0.349
Low in mood	Mild	-0.100	-0.150	-0.051	<0.0005 ^a	-0.022	-0.077	-0.034	0.436
	Moderate	-0.139	-0.203	-0.075	<0.0005 ^a	-0.018	-0.099	-0.063	0.662
	Severe	-0.288	-0.403	-0.173	<0.0005 ^a	-0.020	-0.202	-0.162	0.827
Unable to concentrate, forgetful or confused	Mild	-0.128	-0.173	-0.082	<0.0005 ^a	-0.084	-0.136	-0.033	0.001 ^a
	Moderate	-0.126	-0.196	-0.057	<0.0005 ^a	-0.032	-0.106	-0.042	0.396
	Severe	-0.265	-0.402	-0.128	<0.0005 ^a	-0.046	-0.206	-0.115	0.577
Difficulties in relationships with family or friends	Mild	-0.113	-0.181	-0.045	0.001 ^a	0.003	-0.067	0.073	0.930
	Moderate	-0.229	-0.324	-0.135	<0.0005 ^a	-0.081	-0.183	0.021	0.118
	Severe	-0.170	-0.340	-0.001	0.049 ^a	-0.137	-0.345	0.072	0.199
Tired, fatigued or lacked energy	Mild	-0.074	-0.150	0.002	0.058	-0.047	-0.124	0.031	0.237
	Moderate	-0.143	-0.220	-0.066	<0.0005 ^a	-0.061	-0.147	0.025	0.164
	Severe	-0.223	-0.318	-0.128	<0.0005 ^a	-0.098	-0.210	0.015	0.089
Feeling sick (nauseous/queasy)	Mild	-0.069	-0.121	-0.017	0.010 ^a	-0.024	-0.033	-0.081	0.403
	Moderate	-0.119	-0.184	-0.053	<0.0005 ^a	-0.017	-0.058	-0.092	0.653
	Severe	-0.163	-0.261	-0.065	0.001 ^a	-0.100	-0.029	-0.228	0.127
Constipation	Mild	-0.041	-0.096	0.013	0.136	-0.010	-0.062	-0.042	0.719
	Moderate	-0.095	-0.158	-0.032	0.003 ^a	-0.026	-0.087	-0.036	0.415
	Severe	-0.159	-0.242	-0.076	<0.0005 ^a	-0.056	-0.142	-0.030	0.202
Sickness (vomiting)	Mild	-0.099	-0.157	-0.041	0.001 ^a	-0.036	-0.100	-0.029	0.278
	Moderate	-0.142	-0.217	-0.067	<0.0005 ^a	-0.041	-0.125	-0.042	0.332
	Severe	-0.073	-0.203	-0.057	0.272	-0.088	-0.257	-0.081	0.304
Financial worries	Mild	-0.099	-0.164	-0.034	0.003 ^a	-0.055	-0.116	0.006	0.077
	Moderate	-0.089	-0.163	-0.015	0.018 ^a	-0.025	-0.097	0.047	0.490
	Severe	-0.136	-0.247	-0.026	0.016 ^a	-0.017	-0.125	0.092	0.764

Trouble sleeping	Mild	0.006	-0.048	0.061	0.817	-0.018	-0.068	0.033	0.492
	Moderate	-0.097	-0.158	-0.036	0.002 ^a	-0.049	-0.107	0.008	0.093
	Severe	-0.125	-0.209	-0.041	0.004 ^a	-0.007	-0.099	0.084	0.877
Lost appetite/lost interest in food	Mild	-0.020	-0.071	0.032	0.449	0.016	-0.035	0.067	0.542
	Moderate	-0.105	-0.170	-0.041	0.001 ^a	-0.030	-0.100	0.041	0.403
	Severe	-0.150	-0.252	-0.048	0.004 ^a	0.006	-0.108	0.120	0.914
Diarrhoea	Mild	-0.039	-0.095	0.017	0.173	-0.028	-0.081	0.026	0.309
	Moderate	-0.064	-0.136	0.008	0.079	-0.004	-0.078	0.071	0.918
	Severe	-0.181	-0.296	-0.065	0.002 ^a	-0.003	-0.126	0.119	0.958
Changes to your sense of taste or smell	Mild	-0.002	-0.058	0.054	-0.935	-0.020	-0.034	0.074	0.466
	Moderate	-0.030	-0.092	0.032	-0.345	-0.031	-0.030	0.093	0.315
	Severe	-0.135	-0.216	0.054	0.001 ^a	-0.005	-0.100	0.090	0.916
Sore mouth or tongue	Mild	-0.015	-0.068	-0.039	0.585	-0.021	-0.030	0.072	0.414
	Moderate	-0.049	-0.123	-0.024	0.189	-0.042	-0.030	0.115	0.252
	Severe	-0.140	-0.239	-0.041	0.006 ^a	-0.019	-0.120	0.082	0.711
Pain or irritation at your injection / infusion (needle) site	Mild	-0.014	-0.044	0.071	0.644	0.020	-0.034	-0.074	0.472
	Moderate	-0.062	-0.149	0.024	0.159	0.043	-0.044	0.130	0.329
	Severe	-0.225	-0.373	-0.078	0.003 ^a	-0.116	-0.264	-0.031	0.121
Losing your hair	Mild	0.027	-0.036	0.091	0.394	0.039	-0.019	0.097	0.186
	Moderate	-0.001	-0.072	0.070	0.968	-0.012	-0.080	0.055	0.720
	Severe	-0.072	-0.145	0.002	0.055	0.031	-0.043	0.106	0.405

Note ^a p value statistically significant (p<.050).

Table 5: Associations between chemotherapy-associated problems and supportive care provided.

Problem Type (experienced either moderately or severely)	Do you get asked about your symptoms?			Are all the staff aware who need to know aware of your symptoms?			Do staff provide useful information to help you manage your problems?			Do staff provide useful practical support to help your problems?		
Physical/psychological	Always/ usually % (n=)	Occasionally/ never % (n=)	(Chi²) p=	Always/ usually % (n=)	Occasionally/ never % (n=)	(Chi²) p=	Always/ usually % (n=)	Occasionally / never % (n=)	(Chi²) p=	Always/ usually % (n=)	Occasionally/ never % (n=)	(Chi²) p=
Tired, fatigued or lacked energy	47.0% (148)	65.7% (23)	.035 ^a	47.7% (155)	66.7% (14)	.092	46.9% (150)	69.2% (18)	.023 ^a	46.0% (145)	69.0% (20)	.015 ^a
Changes to your sense of taste or smell	34.3% (106)	37.1% (13)	.436	34.0 (108)	36.4% (8)	.818	33.7% (106)	42.3% (11)	.246	33.2% (103)	46.4% (13)	.116
Trouble sleeping	28.9% (90)	40.0% (14)	.176	27.3% (87)	65.2% (15)	.000 ^a	28.2% (89)	51.9 (14)	.010 ^a	27.3% (85)	53.3% (16)	.003 ^a
Constipation	28.4 (89)	37.1% (13)	.283	28.3% (91)	45.5% (10)	.087	28.3% (90)	38.5% (10)	.273	28.3% (89)	32.1% (9)	.662
Low in mood	19.7% (61)	29.4% (10)	.183	20.5% (65)	17.4% (4)	.720	20.4% (64)	22.2% (6)	.495	19.3% (60)	28.6% (8)	.175
Feeling sick (nauseous/queasy)	22.3% (69)	15.2% (5)	.345	22.6% (72)	9.5% (2)	.159	22.2% (70)	16.0% (4)	.330	21.5% (67)	17.9% (5)	.430
Feeling anxious	21.6% (67)	22.9% (8)	.866	21.6% (69)	22.7% (5)	.904	22.5% (71)	15.4% (4)	.286	21.1% (66)	28.6% (8)	.242
Lost appetite/ lost interest in food	88.5 (69)	11.5 (9)	.345	21.6% (69)	39.1% (9)	.052	87.2 (68)	12.8 (10)	.058	88.0 (66)	12.0 (9)	.185
Unable to concentration, forgetful or confused	13.4% (41)	14.7% (5)	.838	12.8% (40)	18.2% (4)	.468	13.5% (42)	11.5% (3)	.530	13.0% (40)	21.4% (6)	.167
Losing your hair	27.9% (85)	17.6% (6)	.202	27.5% (86)	18.2% (4)	.342	27.1% (84)	26.9% (7)	.985	27.0% (83)	20.7% (6)	.459
Sore mouth or tongue	18.4% (57)	17.6% (6)	.909	18.0% (57)	2.7% (5)	.578	18.5% (58)	19.2% (5)	.547	17.7% (55)	21.4% (6)	.390
Diarrhoea	15.6% (48)	17.6% (6)	.754	14.5% (46)	33.3% (7)	.022 ^a	15.7% (49)	16.0% (4)	.573	14.8% (46)	22.2% (6)	.222
Sickness (vomiting)	14.4% (44)	8.8% (3)	.370	13.5% (42)	21.7% (5)	.207	12.9% (40)	25.9% (7)	.065	13.4% (41)	20.7% (6)	.204
Pain or irritation at your injection/ infusion site	9.1% (28)	18..2% (6)	.098	8.9% (28)	27.3% (6)	.006 ^a	8.9% (28)	19.2% (5)	.089	8.7% (27)	22.2% (6)	.023 ^a
Social/ emotional												
Financial worries	16.1% (26)	15.0% (26)	.006 ^a	14.4% (26)	17.6% (24)	.261	14.9% (29)	17.7% (22)	.298	14.6% (29)	18.3% (22)	.232
Difficulty managing everyday tasks	19.8% (32)	24.6% (43)	.288	18.7% (34)	28.3% (39)	.030 ^a	18.4% (36)	30.2% (38)	.011 ^a	18.5% (37)	30.3% (37)	.011 ^a
Difficulties in relationships with family or friends	6.7% (11)	6.4% (11)	.908	5.5% (10)	8.9% (12)	.167	5.5% (17)	22.2% (6)	.001 ^a	5.2% (16)	24.1% (7)	.000 ^a

Note: ^a p value statistically significant (p<.050).